# Appendix 1: Online Questionnaire

**Patient engagement in emergency medicine research**

Canadian Association of Emergency Physicians – Patient Engagement Panel

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| **What is patient engagement?**  A **patient** is an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.  **Patient engagement** is a meaningful and active collaboration in governance, priority setting, conducting research, and knowledge translation.  Source: [CIHR Strategy for Patient Oriented Research – Patient Engagement Framework](http://www.cihr-irsc.gc.ca/e/48413.html) (2014). |

**1. Have you engaged patients in emergency medicine research activities as partners?**

☐ Yes

☐ No (*Skip to question 7.)*

**2. Which type of patient partners were involved in your emergency medicine research activities?** *Please check all responses that apply.*

|  |  |
| --- | --- |
| ☐ Individual patients | ☐ Patient representatives (i.e., associations, community organizations) |
| ☐ Informal caregivers and/or surrogates |  |

☐ Other stakeholders informing research, please specify:

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| --- |
|  |
|  |

**3. How did you find and recruit the patient partners that were involved in your emergency medicine research activities?**

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| --- |
|  |
|  |

**4. In which emergency medicine research activities were the patient partners engaged?** *Please check all responses that apply.*

**Preparatory phase**

☐ Research network/project governance

☐ Grant/protocol development

☐ Definition of research priorities

☐ Research fundraising

☐ Intervention development

☐ Research design development

☐ Outcome selection

☐ Ethical considerations

**Execution phase**

☐ Intervention implementation

☐ Patient/participant recruitment

☐ Data collection (i.e., tool development, interviews)

☐ Interpretation/analysis of results

**Translation phase**

☐ Dissemination of research results/Knowledge translation

☐ Other activities, please specify:

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| --- |
|  |
|  |

**5. Which role(s) did the patient partners play in your emergency medicine research activities?** *Please check all responses that apply.*

|  |  |  |
| --- | --- | --- |
| ☐ Co-investigator | ☐ Collaborator | ☐ Co-author of scientific articles |
| ☐ Members of a research committee | ☐ Knowledge users | ☐ Research participants |

☐ Other roles, please specify:

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| --- |
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**6. Please describe how the engagement of patient partners has impacted your emergency medicine research activities.**

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| --- |
|  |
|  |

**7. If you were to engage patients in your emergency medicine research activities, would you need support?**

☐ Yes

☐ No *(Skip to question 9.)*

**8. If yes, what type of support would you need?** *Please check all responses that apply.*

|  |  |
| --- | --- |
| ☐ Recruitment of patient partners  ☐ Training for public partners  ☐ Training for researchers  ☐ Access to literature on best practices  ☐ Guidelines on patient engagement | ☐ Financial  ☐ Logistical (i.e., budget planning for patient engagement activities)  ☐ Coordination and facilitation of patient engagement activities  ☐ Evaluation of patient engagement |

☐ Other types of support, please specify:

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| --- |
|  |
|  |

**9. Please describe three perceived benefits of patient engagement in emergency medicine research.**

☐

☐

☐

**10. Please describe three perceived barriers to patient engagement in emergency medicine research.**

☐

☐

☐

**11. In the coming years, I intend to participate in emergency medicine research activities that engage patients as partners.**

☐ Strongly agree

☐ Agree

☐ Neither agree nor disagree

☐ Disagree

☐ Strongly disagree

**12. Which titles apply to you?** *Please check all responses that apply.*

☐ Emergency medicine physician

☐ Working in an academic emergency department

☐ Working in a community emergency department

☐ Working in a rural/remote emergency department

☐ Emergency medicine resident

☐ Emergency medicine researcher

☐ Patient partner

☐ Other, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**13. How many years of work experience do you have since completing residency or graduate studies? \_\_\_\_\_**

**14. What is your gender?**

|  |  |
| --- | --- |
| ☐ Female | ☐ Male |

**15. In general, what type of research do you do?** *Please check all responses that apply.*

|  |  |
| --- | --- |
| ☐ Biomedical research (fundamental research) | ☐ Health services research  ☐ Population and public health |
| ☐ Clinical research/epidemiology |
| ☐ Health technology assessment | ☐ Health research ethics |
| ☐ Knowledge translation | ☐ Health policy |
| ☐ Health informatics |  |
| ☐ Other, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |

**16. Would you accept to be contacted to participate in a short telephone discussion about your experiences with patient engagement in emergency medicine research?**

☐ Yes

**Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Email:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Phone number:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

☐ No

**17. If you have any comments or questions concerning patient engagement in emergency medicine research, please indicate them here:**

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**Thank you!**

# Appendix 2: Qualitative Questionnaire Guide

**Canadian Emergency Researchers Experience with Patient Engagement**

N.B. These questions serve as a guide only. It will be administered by an experienced qualitative researcher who will be able to probe and discuss topics as they arise with participants.

*Preamble:*

*Before we start the interview, can I just check you are comfortable with our conversation being recorded? It is for my purposes only because I can’t write fast enough to capture everything you say. Once the audio file is transcribed, it will be destroyed.*

*Thank you so much for taking the time to speak with me today and for filling out the survey on patient engagement. I’m a researcher at St. Michael’s and a part of the upcoming CAEP Academic Panel on Patient and Family Engagement. The purpose of this interview is for us to get some more in-depth information about experiences with patient and family engagement in emergency medicine research and build a collection of case studies.*

*So just a few things to review: These interviews will be completely anonymous – no one knows whom I am interviewing, and no identifying information about you will be shared with anyone following this conversation. Any identifying information will be removed from the written transcription and all reports. We may use a quote from your interview in a publication or report; however, your identity will not be revealed. All of the information provided by you will be kept strictly confidential, and we hope that you will feel able to speak freely because we genuinely want to hear your perspective. Also, there are no “right” answers to any of my questions – it’s your views that are important. You can choose not to answer any question that you wish, and you may stop the interview at any time.*

*Do you have any questions or concerns before we start? If not, let’s begin:*

1. **To begin, please tell me about your current role and your research?**
   * How would you describe your career position (early, mid, senior)?
   * What are your main topics of research interest?
   * What are your typical funding sources?
2. **Obviously, patient and family engagement in research has become very popular in today’s research environment. What are your thoughts on this?** 
   * Love
   * Hate
   * Indifferent
3. **What was the drive for you to start including patients and family members in your research?**
   * Nature of the study required it
   * Funding requirements
   * Institutional requirements
   * Idea came from patients and/or family member
4. **Could you describe your experience, including patients in your research? (Please give specific examples.)**

* What kinds of roles do the patients typically play?
* To what extent are the patient’s true partners in the research?
* Have there been any changes in your interactions with patients in research over time?
* Have patients ever brought an idea to you?

1. **What do you think is/has been most valuable about engaging patients in your research?** 
   * Has engaging with patients in research changed your research?
2. **What is/has been the most challenging?**
   * Knowledge
   * Identifying patients
   * Financial
   * Timelines
3. **Patient and family engagement in EM research in particular has been scarce – why do you think this is?**
   * Anything specific to EM research?
4. **What kind of support do you have or have you sought out to help you to be successful in engaging patients in your research?**
   * Training
   * Partnering with external groups or institutional committees
   * Literature
   * Peer consultation
   * Is there anything you would like to have or still need?
5. **Where do you think patient and family engagement in EM research will be in 5 years?**

**Thank you very much for your time. We really appreciate you sharing your experiences.**

# Appendix 3: Paper Form for Feedback on Our Recommendations

**Feedback on patient engagement in emergency medicine research panel**

**We are seeking your written feedback on our recommendations.**

**Please make your comments related to any of our recommendations in the spaces below.**

|  |  |  |
| --- | --- | --- |
| **Recommendation number and/or content of the recommendation** | **Do you agree with this recommendation?** | **Your comments** |
|  | * **Yes** * **No** |  |
|  | * **Yes** * **No** |  |
|  | * **Yes** * **No** |  |
|  | * **Yes** * **No** |  |

# Appendix 4: Online Feedback Form Provided After the Conference

# Here is the link to the PDF of the online survey: <https://drive.google.com/file/d/0B62q-esihUvIRVhtaVVTVHB6aFk/view?usp=sharing>

# Appendix 5: List of Strategies to Recruit Patient Partners Used By Canadian EM Researchers

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| --- |
| 1. Newspaper ads, Facebook, other social media |
| 2. Dedicated patient networks (e.g., BC Patient Voices Network, CanROC Patient Engagement Committee) |
| 3. Patient advocacy committee at the hospital or patient advocacy group at the provincial/national level |
| 4. Physician’s personal contacts, friends, family, colleagues |
| 5. University networks |
| 6. Medical associations, organizations and foundations (e.g., Heart and Stroke Foundation) |
| 7. Emergency Medical Services partners |
| 8. Past research participants |
| 9. ED waiting room, in the ED or after discharge from ED |
| 10. Patient’s social network |

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# Appendix 6: List of Identified Knowledge Gaps About Patient Engagement in EM Research

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| --- |
| * Need for better reporting about how patients are engaged and how to report the impact of their engagement * Need for better indicators and measurements of successful patient engagement * Need to develop and evaluate different training methods, information, and education and other support tools for patients and researchers wishing to engage patients * Need to address the barriers to patients’ ideas influencing research agendas * Need for prospective comparative studies of different methods for engaged patients * Need for strategies to manage conflicts between patients and researchers |

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